

Living with  
**Alzheimer's**



Cure in Mind. Cure in Sight.

**BrightFocus Foundation** is the new name for the nonprofit American Health Assistance Foundation, celebrating 40 years of support for health research and public education. The new BrightFocus name reflects our continued commitment to advancing knowledge that saves mind and sight. Our three programs—Alzheimer’s Disease Research, Macular Degeneration Research, and National Glaucoma Research—focus on the toughest challenges facing brain and eye health.

# Living with **Alzheimer's**

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# Introduction

**Each year, the number of people with Alzheimer's disease increases.**

Currently, an estimated 5.4 million Americans are living with this degenerative brain disorder. Worldwide, nearly 36 million people are believed to be living with Alzheimer's disease or other dementias. Already, nearly one in two people (43 percent) age 85 and older in the U.S. have Alzheimer's, and this age group is among the fastest-growing segments of the population. By the year 2050, more than 15 million Americans could be living with Alzheimer's, and 115.4 million people worldwide are expected to have Alzheimer's or other dementias.

In the past, there were many misconceptions about Alzheimer's disease. The symptoms were thought to be an inevitable and usual part of growing old. Although mild memory delays and forgetfulness are often associated with the elderly, these should not be confused with the progressive deterioration associated with Alzheimer's disease, which involves a range of symptoms that go beyond mere memory lapses. We



now understand that Alzheimer's is a specific disease primarily connected with aging.

In 1906, the German physician Alois Alzheimer first identified, through an autopsy of one of his patients, a collection of plaques surrounding the brain's nerve cells and tangled fibers within the cells. The disease affecting these brain cells would eventually bear his name.

Since this discovery, there have been many scientific breakthroughs in Alzheimer's disease research. In the 1960s, scientists discovered a link between cognitive decline and the number of plaques and tangles in the brain. The medical community then formally recognized Alzheimer's as a disease and not a normal part of aging. In the 1970s, scientists made great strides in understanding the human body as a whole, and Alzheimer's emerged as a significant area of research interest. This increased attention led, in the 1990s, to important discoveries and a better understanding of complex nerve cells in the brains of Alzheimer's patients. More research was done on Alzheimer's susceptibility genes, and several drugs were approved to treat the cognitive symptoms of the disease.

Over the last decade, scientists have made substantial progress in understanding potential environmental, genetic, and other risk factors for Alzheimer's disease, and the processes leading to formation of plaques and tangles in the brain. Specific genes related to both the early-onset and late-onset forms of Alzheimer's have been identified, and more

effective treatment options have been approved by the U.S. Food and Drug Administration (FDA). However, Alzheimer's disease is still incurable. The drugs currently in use treat only the symptoms, not the cause, of the disorder, and they only temporarily slow the progression of cognitive decline.

As our understanding and knowledge of Alzheimer's disease grows, scientists are homing in on the possible root causes of the disease. More effective drugs with fewer side effects are likely to emerge over the next several years. These drugs may not prevent or reverse the disease, but could act to substantially slow its progress. Furthermore, through increased investment in research, the road to a breakthrough discovery leading to a cure may be shortened.

BrightFocus offers a free resource list containing information on several organizations that can help deal with aspects of Alzheimer's disease, including caregiving, long-term care facilities, financial and legal issues, and clinical trials. See the end of this booklet for more information.



## Alzheimer's Disease—

# Description, Risk Factors, and Mitigating Risk



## Description

Alzheimer's disease irreversibly destroys brain function and eventually leads to complete brain failure. During an autopsy in which scientists examine the brains of people with Alzheimer's under a microscope, they see two types of abnormalities: *neuritic plaques* outside the brain's nerve cells or neurons and *neurofibrillary tangles* within the neurons. Neuritic plaques

are spherical structures consisting of a protein called *beta amyloid* and cellular material. Neurofibrillary tangles are twisted fibers of another protein called *tau*. These plaques and tangles, the hallmarks of Alzheimer's disease, seem to interfere with communication among neurons in the brain, thereby disrupting mental activity. This loss of connection appears to damage the functioning of these neurons and leads

to their eventual death. Scientists are not entirely sure whether these plaques and tangles are a cause of Alzheimer's or are caused by it. However, much research is focused on stopping the accumulation of these proteins or preventing them from turning toxic.

Brain images of those with Alzheimer's disease show degeneration in regions vital to memory formation, which explains why Alzheimer's patients have trouble learning new facts and retaining short-term memories. Later in the disease, these images also reveal degeneration of the frontal lobe, which acts as the "executive" of the brain. Alzheimer's disease affects a person's cognition—the process of knowing—including awareness, perception, reasoning, and judgment, as well as personality, behavior, and

communication. As the frontal lobe deteriorates, the individual exhibits symptoms such as poor organization and planning, distractibility, irritability, and apathy.

Many people in the field use stages in its evolution (see page 12) when discussing the many issues related to Alzheimer's disease. As the disease advances, the patient's abilities decline.



## Known Risk Factors

Scientists have identified factors that appear to play a role in the development of Alzheimer's, but have not yet reached any firm conclusions as to the exact causes of this complex disease. There are likely many contributing factors, rather than a single cause. These include:

- ▲ **Age:** The single greatest risk of developing Alzheimer's disease is age. Approximately six percent of Americans between the ages of 65 and 74 are thought to have Alzheimer's disease; for those age 85 and older, the estimates range from 35 percent to nearly half.
- ▲ **Genetics:** The majority of Alzheimer's cases are late-onset, usually developing after age 65. Late-onset Alzheimer's disease has no known cause and shows no obvious inheritance pattern. In some families, however, clusters of cases are seen. A gene called *Apolipoprotein E* (ApoE) appears to be a risk factor for the late-

onset form of Alzheimer's disease. There are three forms of this gene: ApoE2, ApoE3, and ApoE4. Roughly one in four Americans has ApoE4 and one in twenty has ApoE2. While inheritance of ApoE4 increases the risk of developing Alzheimer's, ApoE2 substantially protects against the disease. Some current research is focused on the association between these two forms of ApoE and Alzheimer's. Familial Alzheimer's disease (FAD), or early-onset Alzheimer's, is an inherited, rare form of the disease, affecting fewer than 5 percent of Alzheimer's patients. FAD develops before age 65 and can strike people as young as 30. It is caused by mutations of one of three genes on chromosomes 1, 14, and 21.

## Potential Contributing Factors

▲ **Cardiovascular disease:** Risk factors associated with heart disease and stroke, such as high blood pressure and high cholesterol, may also increase the risk of developing Alzheimer's disease. High blood pressure may damage blood vessels in the brain, disrupting regions that are important in decision-making, memory, and verbal skills, which could contribute to the progression of Alzheimer's. High cholesterol may inhibit the ability of the blood to clear protein from the brain.

▲ **Type 2 diabetes:** There is growing evidence of a link between Alzheimer's disease and type 2 diabetes. In Type 2 diabetes insulin does not work effectively to convert blood sugar into energy. This inefficiency results in production of higher levels of insulin and blood sugar, which may harm the brain and contribute to the progression of Alzheimer's.

▲ **Oxidative damage:** Free radicals are unstable molecules

that sometimes result from chemical reactions within cells. These molecules seek stability by attacking other molecules, which can harm cells and tissue and may contribute to the neuronal brain cell damage caused by Alzheimer's disease.

▲ **Inflammation:** Inflammation is a natural but sometimes harmful healing function in which immune cells rid tissues of dead cells and other waste products. As protein plaques develop in Alzheimer's disease, inflammation results. It is not known whether this process is damaging and a cause of Alzheimer's or part of an immune response attempting to contain the disease.

▲ **Other possible risk factors:** Some studies have implicated prior traumatic head injury, lower education level, stress, and female gender as possible risk factors. Alzheimer's disease may also be associated with an immune system reaction or a virus.

## Mitigating Risk Through a Healthy Lifestyle

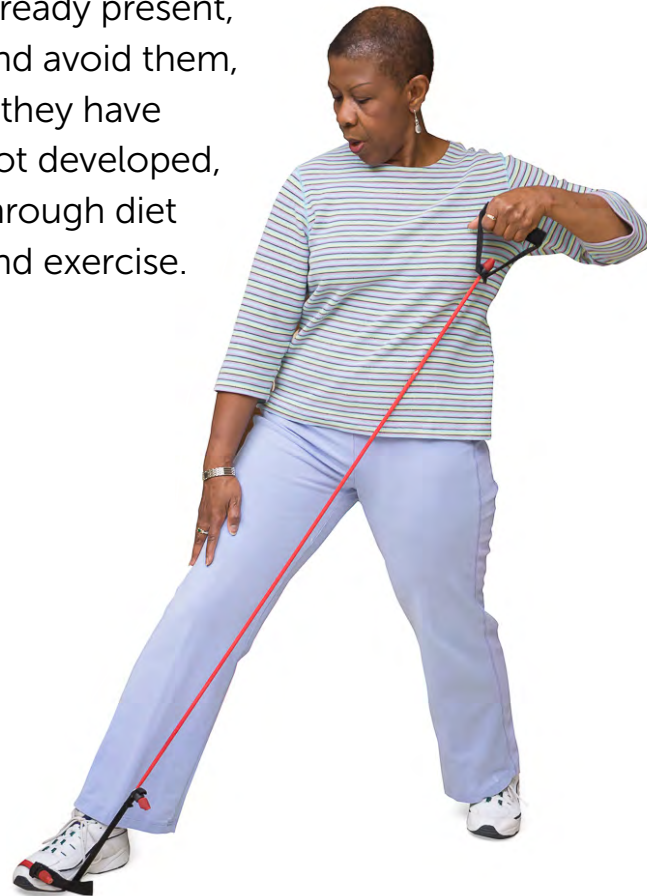
While the known risk factors for Alzheimer's disease—aging and genetics—are not controllable, numerous studies indicate that a healthy lifestyle may lower the risk of developing Alzheimer's. It's important to keep the body and mind in good shape through good nutrition, sufficient exercise, avoidance of smoking, controlling certain physical conditions, and engaging in mental and social activities.

▲ **Diet:** It is recommended that one eat a varied diet that includes plenty of fruits and vegetables; legumes (for example, beans, peas, and seeds); fruits; whole grain and fish; and is low in saturated fat and added sugar. Foods that contain omega-3 fatty acids—such as tuna and salmon; certain oils, nuts, and seeds; and the antioxidant vitamins A, C, and E—may also be beneficial.

▲ **Exercise:** Physical activity reduces the risk of many diseases, helps maintain a healthy weight, and enhances mental fitness. A combination of moderately intense

aerobic exercise, strength training, and activity that increases flexibility is recommended.

▲ **Physical conditions:** Research has shown that vascular disease, stroke, high blood pressure, high cholesterol, and diabetes may all be associated with an increased risk of developing or worsening Alzheimer's. Control these conditions if they are already present, and avoid them, if they have not developed, through diet and exercise.



Depression and stress can lead to physical problems and have also been linked to Alzheimer's, so they should be treated if necessary.

- ▲ **Social connections:** Health benefits arise from maintaining and increasing social connections with family and friends through creative and intellectual pursuits, such as crafts and hobbies; playing cards and games; attending plays, musical performances and lectures; and visiting parks and museums.

- ▲ **Mental activity:** It is possible to build up brain "reserves" by continuing to enjoy favorite pastimes and engaging in new and challenging activities such as playing board, card, and video games; solving puzzles; reading, writing, and corresponding; and even conversing and singing. Taking a class, learning to play a musical instrument, or taking up a new hobby all benefit health and mood. Choosing enjoyable activities makes it easy to stick to a plan for good health.

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Currently, there is no known treatment that will cure Alzheimer's disease. However, there are medications that can help control its symptoms.

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## Alzheimer's Disease—

# Diagnosis, Stages, Treatment, and Research



## Diagnosing Alzheimer's Disease

Many people recently diagnosed with Alzheimer's may have felt for some time that "something isn't right." They may have become more forgetful, found themselves easily disoriented, had unexpected lapses in judgment, or experienced unusual mood swings and emotions. These can be early signs of dementia, but they can also be signs of depression or other

treatable conditions. In addition, some dementias are caused by dehydration, drug reactions, hypothyroidism, infection, or other physical problems. These dementias can be reversed.

A physician, through a complete examination, can rule out other conditions with similar, Alzheimer's-like symptoms. Although a true



diagnosis can only be made by doing a brain autopsy, physicians can correctly diagnose Alzheimer's disease in nine out of 10 cases through examination and testing. Early diagnosis and treatment are important, because current drugs appear to be most effective at slowing cognitive decline when taken in the first stages of the disease.

A thorough evaluation for Alzheimer's disease will include physical, neurological, and psychological testing:

- ▲ a physical examination, including blood, urine, liver, and thyroid tests; memory, language, problem solving, attention, and counting tests;
- ▲ depression screening; and
- ▲ brain imaging.

It is entirely appropriate to ask for a referral to a specialist for this testing if the primary care physician is not experienced with conducting them, or to go directly to a specialist in the first place.





## Types of Specialists

There are many medical professionals who may be able to help with diagnosis and afterward. Each is trained in different specialties, including those called a neurologist, neuropsychologist, gerontologist, geriatrician, geriatric nurse practitioner, geriatric psychologist, or gero-psychologist.

A good place to start a search would be with the American Medical Association's web-based "DoctorFinder" to search for physicians by name, location, or specialty (neurology is an option). The American Academy of Neurology website has a search on its "Patients & Caregivers" page called "Find a Neurologist In Your Area," where you can choose "Alzheimer's Disease" as a specialty. Other options are the American Psychological Association website with a "Psychologist Locator Search" and the American Geriatrics

Society website with a "Find a Geriatrics Health Care Provider Referral Service."

Please note that describing options for finding a specialist to fit an individual's or family's needs does not constitute an endorsement or recommendation by the BrightFocus Alzheimer's Disease Research program or the BrightFocus Foundation, and the organization is not responsible for the content of any referenced website.

## Stages of Alzheimer's Disease

Common early symptoms of Alzheimer's include confusion, disturbances in short-term memory, problems with attention and spatial orientation, personality changes, language difficulties, and unexplained mood swings. Recently, scientists have identified a condition that falls between normal age-related memory loss and dementia, called *mild cognitive impairment* (MCI). Individuals with MCI have persistent memory problems (for example, marked forgetfulness and difficulty remembering names and following conversations), but are able to perform routine activities without more than usual assistance. MCI often leads to Alzheimer's, but while all those who progress to some form of dementia go through a period of MCI, not all patients exhibiting MCI will develop Alzheimer's disease.

From three to fifteen stages and sub-stages have been identified for Alzheimer's disease. The four stages listed below represent the general progression of the disease, beginning before symptoms are perceptible. However, since Alzheimer's disease

does not affect everyone in the same way, these symptoms will likely vary in severity and chronology. There will be fluctuations, even daily, and overlap of symptoms. Some people will experience many symptoms, others only a few, but the overall progression of the disease is fairly predictable. On average, Alzheimer's patients live for eight to ten years after diagnosis, but this terminal disease can last for as long as 20 years.

In all stages, symptoms generally relate to progressive impairment of mental processes and memory function, communication problems, personality changes, erratic behavior, dependence, and loss of control over bodily functions.

**Pre-symptomatic** Physical conditions connected to Alzheimer's disease exist in a person's body long before symptoms are evident. State-of-the-art equipment is being developed to detect subtle signs of Alzheimer's prior to noticeable memory loss. From the patient's perspective, Alzheimer's disease can be described in three general stages of progression:

▲ **Mild (stage 1)** In addition to minor memory loss and difficulty learning, first-stage Alzheimer's disease may cause a loss of energy and spontaneity, as well as mood swings, confusion, trouble communicating, and difficulty organizing. Those with Alzheimer's disease may become withdrawn, avoiding new people and places in preference for the familiar. Understandably, they can also become angry and frustrated.

▲ **Moderate (stage 2)** During the second stage of Alzheimer's disease, the patient begins to need help carrying out anything but simple tasks. Recent events and personal histories may be lost and the present confused with the past. There may be difficulty recognizing familiar people, as well as in speaking, reading, writing, and dressing, and difficulty sleeping well. A person with moderate Alzheimer's disease is clearly becoming disabled.

▲ **Severe (stage 3)** Third-stage Alzheimer's disease brings full-blown disability, with possible loss of the ability to feed oneself, to speak, to recognize people, and to control bodily functions. Memory weakens still further and may nearly disappear. The patient's weakened physical state creates vulnerability to other diseases and breathing problems, especially for those confined to bed.



## Current Medical Treatments for the Symptoms of Alzheimer's Disease

Currently, there is no treatment known to cure Alzheimer's disease. However, there are medications that can help control its symptoms. In addition, medical treatments are also available to help manage agitation, depression, or psychotic behavior (hallucinations or delusions), which may occur as the disease progresses. Before taking any medications, over-the-counter drugs, supplements, or herbs, consult a physician for a thorough evaluation in order to make an informed decision.

There are five FDA-approved drugs used to treat Alzheimer's disease. Four of them, called *cholinesterase inhibitors*, are designed to regulate symptoms and delay the course of Alzheimer's: Cognex® (tacrine), Aricept® (donepezil), Exelon® (rivastigmine), and Razadyne® (galantamine). These drugs slow the metabolic breakdown of acetylcholine, an important brain chemical involved in nerve cell communication. Those suffering from Alzheimer's have low

levels of acetylcholine, and these drugs make more of it available for communication between cells. This may help slow the progression of cognitive impairment and be temporarily effective for some patients with Alzheimer's. However, as Alzheimer's disease further develops, less acetylcholine is produced, and the drugs tend to lose their efficacy.

All four of the above medications are approved for the treatment of mild to moderate symptoms of Alzheimer's disease in its early stages. They are aimed at slowing degeneration and even improving mental function, including thinking, judgment, recognition, and memory. Effectiveness and results vary from person to person, and some drugs may be better tolerated than others by certain individuals. Side effects can include nausea, dizziness, headache, fatigue, insomnia, muscle cramps, and weight loss.

Cognex, though effective, has more adverse side effects than the other medications and, although still available, is now rarely prescribed. Aricept appears to have a limited slowing effect on the progression from mild cognitive impairment to Alzheimer's. Individuals with MCI have memory problems, but are able to independently perform daily activities; however, MCI often leads to Alzheimer's disease. In 2006, the FDA also approved Aricept for the management of severe Alzheimer's symptoms.

Namenda® (memantine) is the fifth FDA-approved drug and is used for the treatment of moderate to severe Alzheimer's. Namenda is an N-Methyl-D-Aspartate (NMDA) *receptor antagonist*. NMDA receptors control the actions of a chemical messenger called glutamate that is released in large amounts by Alzheimer's-damaged brain cells. Namenda

appears to protect the nerve cells against excess amounts of *glutamate*. Side effects may include fatigue, dizziness, and headache.

All of these Alzheimer's drugs are administered orally. However, in 2007 the FDA approved the use of an Exelon patch that delivers medication through the skin.

Depression is common in the early stage of Alzheimer's, and it can be treated. For individuals in the middle stages of the disease, there are also medications to control depression, anxiety, and psychotic behavior, including paranoid thoughts, delusions, and hallucinations. The patient can also become agitated and resistant to care, which may escalate into combativeness. Medications for these symptoms are considered when non-medication alternatives have failed and/or these symptoms put the person with Alzheimer's or others in danger.

## Research on Potential Treatments for Alzheimer's Disease

There is a strong Alzheimer's disease research community, and many potential treatments are being investigated in laboratories and in human clinical trials. Scientists continue basic research on therapies that could potentially clear the protein plaques in the brain. The safety and efficacy of possible treatments are being tested on humans, including drugs that could remove plaques, immunotherapy (vaccination) with beta amyloid antibodies, non-steroidal

anti-inflammatory drugs (NSAIDs), and statins (drugs used to lower cholesterol). The protective effects of antioxidants (vitamins A, C, and E) and omega-3 fatty acids (found mainly in fish such as tuna and salmon) are also being tested in trials. To date, no consistent results have emerged from various studies, but further research and future results from rigorous trials should help clarify the benefit of these and other prospective treatments.

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Those who have accepted the terminal nature of the disease often find an inner peace and a greater sense of perspective. They are able to prepare themselves and their families and live much more fully.

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# Emotional Impact of Diagnosis

**Upon a diagnosis of Alzheimer's, the individual and family members will need time to prepare emotionally for the progressive and terminal nature of this disease.**

The person with Alzheimer's and his or her loved ones will likely be overwhelmed and need time to absorb the news. Descriptions of some normal and common initial emotions follow.



## Effect on Those with Alzheimer's Disease

It may take time to work through the stages normally associated with the diagnosis of a terminal illness: denial and isolation; anger and resentment; "bargaining"; depression; and, finally, acceptance. In moving through the stages of adjustment, patients need to reach out for support to family and friends, as well as to professionals, such as physicians and counselors. It often helps to talk in support groups to others with the disease. Many people worry less as they gather more information. Some patients derive comfort from spiritual consultation, and those who don't belong to formal religious groups can still gain insight and perspective from religious and philosophical texts. Formal counseling, as well as heart-to-heart discussions with close friends, can also be very helpful.

Those who have accepted the terminal nature of the disease usually find an inner peace and a greater sense of perspective. They are able to prepare themselves and their families and live much more fully than those in denial

(that is, those denying that they have the disease or refusing to accept the meaning of the diagnosis). Those accepting and learning about the diagnosis realize there will be time to continue enjoying life, to make important plans and decisions, to engage in pleasurable activities, and to come to closure or completion in many areas. Additionally, some individuals with mild Alzheimer's gain satisfaction by becoming advocates for research and care through volunteer activities, speaking engagements, and lobbying efforts.

Many or even most recently diagnosed patients choose to wait before telling family members about their illness. For some, letting others know may bring a sense of finality to the diagnosis. Revealing this information to family members can be emotionally painful for all concerned, and everyone will need to work through their own feelings about the illness. This is a difficult time, but generally individuals with Alzheimer's feel a sense of relief when the information is shared and no longer concealed.

## Effect on Family Members

If there is a spouse, she or he will likely need to work through strong emotions related to the diagnosis. Many times spouses also have to deal with their own health problems. They may fear a future that will be very different from the one they had planned. Husbands and wives often are required to reverse roles and take on unfamiliar tasks. Depending on their relationship, a diagnosis of Alzheimer's can bring couples closer together or it can alienate them. Spouses need to accept that the person they have known and loved may change dramatically in personality and behavior, and there will almost without doubt come a time when their loved one does not recognize them. The spouse may appreciate getting together with others in a similar situation to converse and to discuss these feelings. He or she may seek offers of help with meals, transportation, and other tasks, as well as simple, kind acts such as visits and respite. Caregiver training and support groups can also be very helpful and are recommended. In some cases, professional counseling may be needed.



Adult children will also need to adjust to the role reversal in caring for a parent. They may feel overwhelmed by the looming responsibilities of working within or outside the home, caring for their own children, and helping their parent. They may feel angry at the burden falling to them. Adult children who do not live close by may feel guilty, not fully comprehend, or perhaps even deny the realities of the disease. Family members should



support the main caregiver and offer help; those at a distance can undertake those tasks that do not require proximity. As distressing as a parent's Alzheimer's diagnosis can be, this is the time to begin to accept the future, build a support network, gather information to help alleviate fears, and plan for the road ahead.

Children and adolescents are also affected; they may feel sad, frustrated, angry, or afraid if someone in the family, a grandparent for example, is diagnosed with Alzheimer's.

Younger family members should be encouraged to ask questions and express feelings, which should be honestly addressed. They need to understand that although the loved one may act differently, there are still activities they can enjoy with their relative, such as helping with chores, listening to music, or reading a book. Teachers and guidance counselors should be made aware of the situation. There are also books and support groups that deal specifically with young people.



# Planning for the Future

**The amount of time it takes to adjust to a diagnosis of Alzheimer's will vary from person to person, both for those with the disease and their loved ones.**

Open communication and information sharing among everyone involved can help determine when the time is right to begin planning for the future. Certain matters should be taken care of as quickly as possible, and although it may seem daunting, breaking down tasks and dividing responsibilities can alleviate some stress.

As a starting point, family members may want to meet with the patient to discuss his or her needs and wants, decide on a care plan, sort responsibilities, build a support network, and find outside resources. A mediator or objective third party can be helpful. The family may consider hiring a professional geriatric care manager (GCM), who can evaluate the situation and identify solutions for various aspects of long-term care.

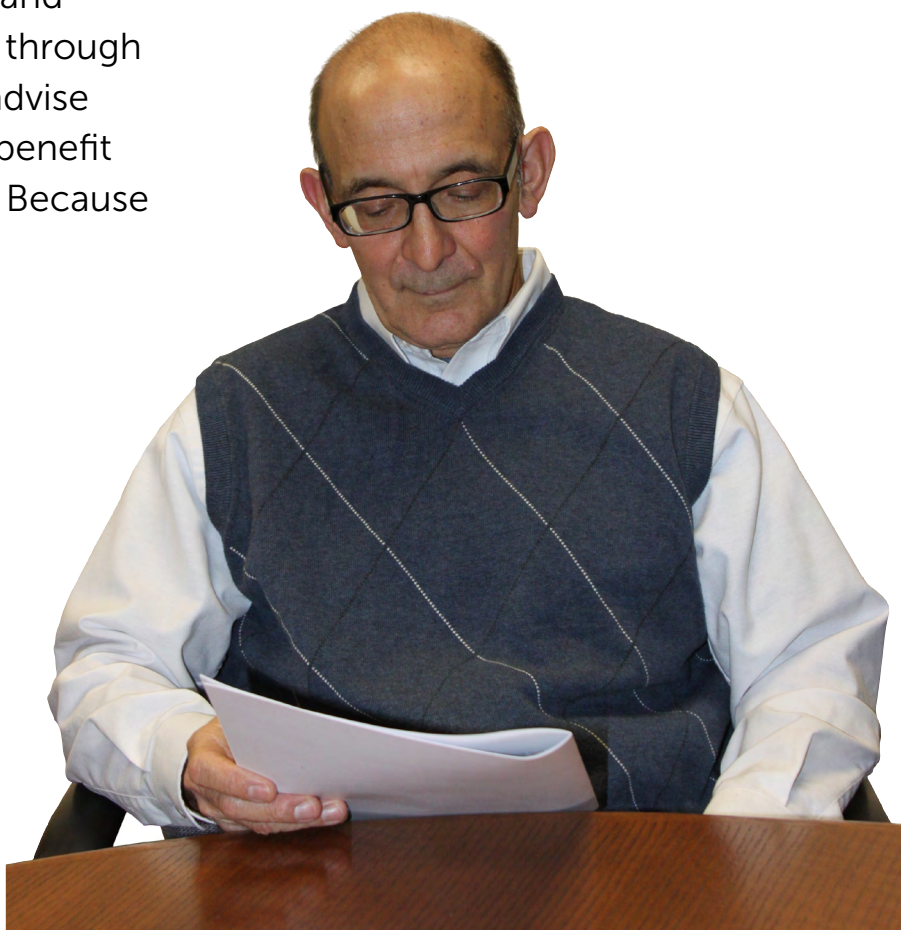
Generally, these care managers charge an intake fee and an hourly rate based on location, their qualifications, and the extent of services. Some organizations may subsidize the cost. The BrightFocus Alzheimer's Disease Resource List includes information on finding GCMs.

A long-range plan should include gathering important financial, legal, and health information; identifying responsibilities; finalizing legal documents (advance directives); and discussing long-term caregiving options.

## Employment

When first experiencing Alzheimer's symptoms, a worker should consult a lawyer to determine rights and responsibilities. For instance, in some cases an employer may have to provide accommodations, while in others an employee may be at risk for discharge. Also, it may prove useful for the worker to discuss with an attorney whether insurance, retirement, and disability benefits are available through work and/or federal laws—such as the Americans with Disabilities Act and Family Medical Leave Act—and through state programs. A lawyer may advise an employee to obtain further benefit information from an employer. Because

Alzheimer's is a degenerative disease, it may be advisable to bring a trusted family member or friend to meetings, although an attorney sometimes may advise against the presence of third parties in order to preserve attorney-client privilege.





# Gathering Important Information

Soon after a diagnosis, financial, legal, and health records need to be put in order. The following information should be gathered and kept together in a single place that is known to at least two family members, caregivers, or trusted friends.

## General

- ▲ Name, address, and Social Security number
- ▲ Driver's license, passport, birth certificate, and marriage certificate, if any
- ▲ Insurance information—including Medicare and Medicaid numbers—and life, health, homeowner's, and automobile policies and policy numbers
- ▲ Veterans Administration claim number, if applicable
- ▲ Names, addresses, and phone numbers of lawyers, financial advisors or accountants, and insurance agents

## Financial

- ▲ Bank records, including all bank account numbers. Consider giving a general and durable power of attorney and an advance directive for health care that will permit trusted family or friends to assist with finances and health care decisions and possibly preserve savings, should the patient need long-term care. If the patient loses capacity and doesn't have such documents in place, a costly and intrusive guardianship through the courts may be required. In some cases it may be advisable to put assets in the name of a spouse or other loved one, but legal advice is essential before doing any financial planning of this type.
- ▲ Information on all sources of income, including pension plans, IRAs, Keogh plans, and stock certificates

## **Tax records**

- ▲ Information on property owned (including real estate), mortgage payments, or titles to property
- ▲ Credit cards and account numbers, including personal identification numbers (PINs) and security codes
- ▲ Information on all loans or outstanding debts, and on money owed to the patient
- ▲ Receipts/documents for any pre-paid funeral/burial arrangements, if applicable

## **Legal**

- ▲ Copies of the will or information on its location; advance medical directives; durable power of attorney for health and/or finances; and burial requests (mortuary, burial plot, and deed)

## **Health**

- ▲ Names, addresses, and phone numbers of physicians, hospitals, etc.
- ▲ Information pertaining to medical history, medications and dosages, and medical devices

## Division of Responsibilities

To alleviate some of the stress of dealing with the future, the family may want to hold a meeting to discuss plans and division of caregiving responsibilities. No one can predict what will be needed for every stage of the disease, so emphasis should be on the immediate future, while considering possibilities for the longer term. Prior to the meeting, gather information and resources. Be sure to include the person with Alzheimer's in the discussions, but keep in mind that the individual may be resistant to suggestions and still overwhelmed emotionally. Other family members should allow him or her to express needs and desires, keep their minds open, and make positive suggestions. Disagreements will almost inevitably occur, but everyone should be encouraged to voice their opinions and make recommendations.

Each member should honestly assess personal preferences, financial abilities, and time availability to determine his or her appropriate role. Draft a written plan that includes

decisions on allocating responsibilities (on-site and long-distance), costs, and time commitments. These responsibilities can be divided as follows: medical needs, including communication with physicians and keeping track of medical records; daily living activities (bathing, dressing, etc., as well as cleaning, meal preparation, transportation, and shopping); and financial and legal issues. Although a written plan is recommended, it should also be adaptable to the person's changing needs and those of caregivers. Put a system in place to ensure essential, regular communication among family members.

As much as possible, family members should be supportive of one another, offering assistance and respite to the primary caregiver, and staying up to date on the physical and emotional condition of the person with Alzheimer's. They should take advantage of the many resources available for caregiver support, including those listed in the BrightFocus Alzheimer's Disease Resource List.

## Home Safety

The safety of the home can be a concern for some Alzheimer's patients, particularly if they begin to wander. Caregivers should do a room-by-room safety check and periodically reassess needs as the disease progresses. Not all changes must be made immediately; some will be more appropriate in the later stages of Alzheimer's. It is possible to modify and adapt the home while keeping the surroundings familiar and comfortable.

The following are general precautions, to be instituted as appropriate

- ▲ Keep important and emergency phone numbers handy.
- ▲ Ensure adequate lighting throughout the home; install night lights.
- ▲ Keep entryways, halls, and floors free of clutter, extension cords, and scatter rugs; avoid placing furniture in walking areas.
- ▲ Secure locks on windows and doors; keep a spare key hidden outside the home, or give one to a neighbor or nearby friend.
- ▲ Use childproof locks for toxic substances, medications, and alcohol.
- ▲ Ensure that smoke and carbon dioxide detectors are in working order.
- ▲ Install handrails on stairs, grab bars in bathrooms, and other devices designed for those who need physical assistance.
- ▲ Remove and safely store potential hazards such as weapons, plastic bags, and power tools.
- ▲ Protect computers and information stored on them.
- ▲ Consider labeling doors to rooms such as "bedroom," "bathroom," etc.
- ▲ Ensure that emergency plans are in place.

If the Alzheimer's patient begins to wander, extra precautions need to be taken to secure the home. Many companies offer safety devices such as double locks, alarms, and items used to disguise exits. An identification or medical bracelet for the individual is also a good idea. Neighbors, local

merchants, and police should be notified in case the person manages to leave the home without a companion. The BrightFocus Alzheimer's Disease Resource List includes websites with more information and products for ensuring home safety.



## Driving Safety

Deciding when the person with Alzheimer's should stop driving can be difficult, and the situation should be calmly and positively discussed, ideally before problems arise. Many people in the very early stages of the disease may be able to continue driving safely, but even then they should stay on familiar short routes in daylight and good weather. As the disease progresses, driving ability needs to be carefully observed and reassessed. Consider the person's reflexes, coordination, reaction time, eyesight, hearing, and ability to orient him- or herself. Recurring problems such as making slow decisions, failure to observe traffic signals, and hitting curbs are warning signs.

When driving becomes unsafe, it may be necessary to enlist an authority figure (such as a physician or police officer) to reinforce the decision. To ease the transition, investigate and offer alternative

forms of transportation, and reduce the number of activities that require driving. For example, prescriptions and groceries can be delivered rather than picked up at a store. Driving is often part of an individual's social life, so try to find other ways to continue these interactions, such as asking friends and family to visit. If the person insists on keeping the car keys, it may be necessary to give him or her keys that don't work, temporarily park the car elsewhere, or disable the engine.





## Financial Matters

Planning for the financial future of Alzheimer's disease is extremely important. There are costs associated with medical professionals, prescriptions, assistance in or outside the home, and long-term living arrangements, all of which can add up and drain personal savings very quickly. As early as possible, gather information on all means of payment and decide which are best. In addition, caregivers and other family members should review their own finances to determine whether and how much they can contribute. The recommendations below should not replace professional advice, and those affected should consult an elder law attorney and possibly a financial adviser. For a list of organizations that provide financial information and assistance for older Americans, see the BrightFocus Alzheimer's Disease Resource List.

### Some payment options include:

#### Government benefits programs

Medicare is a federal health insurance program available to most Americans age 65 or older, people with end-stage renal failure, and people who have received Social Security Disability benefits for two years. To receive Medicare assistance, specific eligibility requirements must be met. Medicare covers some, but may not cover all, of the services a person with Alzheimer's may require. Prescription drug coverage is also available.

Medicaid is a joint federal and state program—administered by state agencies—for certain individuals and families with low incomes and resources. Basic eligibility and benefit rules apply in all states, but eligibility criteria and ancillary benefits can vary from state to state. Medicaid can cover all or a portion of nursing home costs, assisted living expenses, as well as some in-home care. Individuals must

have limited income and savings to qualify for Medicaid but with advance planning, it often is possible to preserve significant amounts of money for loved ones. Generally, starting Medicaid planning at the early stages of diagnosis preserves options and maximizes potential savings. Because Medicaid law is highly complex and unintuitive, it may be desirable to consult an elder law attorney for help in preserving assets.

Social Security is a federal program that provides retirement income, disability payments, and other payments to workers who contributed to the plan when employed, and to some dependents and disabled children..

Veterans' benefit programs may be applicable.

### **Private insurance plans**

Medigap is health insurance sold by private companies to supplement, or fill the "gaps," in Medicare coverage.

Managed-care health insurance

includes preferred-provider plans and health maintenance organizations.

Long-term care insurance is an option if it was in place at the time of the Alzheimer's diagnosis.

### **Loans and personal savings**

Life insurance policies: There are several ways to obtain loans from these policies that do not have to be repaid until death.

Mortgages: While not always recommended, it is possible to borrow money against the equity in a home through a reverse mortgage. There are a wide range of rates and terms, which should be carefully investigated. Consult with an elder law attorney and a financial planner or accountant, as well as your executor and, perhaps, primary beneficiaries, before making such an important financial decision.

Personal assets: These can include income from stocks and bonds, sale of property, savings accounts, and retirement accounts.

## Legal Matters

Ideally, the legal documents described below will be in place before a diagnosis of Alzheimer's. If not, the patient and a caregiver or companion should consult a lawyer as soon as possible, because legal instruments cannot be completed once a person is legally incompetent. Those in the early stages of the disease are not automatically assumed to be incompetent, and they will probably be able to understand the issues and make decisions.

The information provided below contains general statements and does not constitute legal advice. A family lawyer may be retained for legal advice, but there are also attorneys who specialize in elder law. Lawyers can help interpret state laws and ensure that the wishes of the patient are carried out. Elder law attorneys are experts in legal matters of the aging, such as long-term care, Medicare, Medicaid, taxes, and estate planning. Local Area Agencies on Aging may be able to provide referrals for legal advice, and

low-cost legal services are available through state legal aid societies. (Area Agencies on Aging were established through the federal Older Americans Act to help Americans 60 and older live independently at home.) The BrightFocus Alzheimer's Disease Resource List contains more information on elder law attorneys and legal assistance.

Although newly diagnosed people will likely be emotionally distressed, they should still be encouraged to actively participate in these legal discussions. This may lead to a sense of greater control and calmness. Those who may already be slightly impaired should be involved as much as possible and will likely be capable of making at least some decisions. If the Alzheimer's patient resists taking action, a firm but understanding family member, good friend, or objective professional may be required to ensure a secure legal future. In all cases, individuals with Alzheimer's need to be extremely careful in choosing those who will act as their agents and in deciding which powers will be granted.

Legal medical directives should include establishing an advance health care directive (also known as a living will). Legal financial documents—a durable power of attorney for finances, a will, and possibly a living trust—also need to be finalized if they are not already in place. These documents should be revisited periodically to ensure they

are up to date. Since state laws vary, the documents may need to be re-examined if the person moves. Family members or caregivers should know where the originals are located and have copies. The patient’s physician should have copies of health-related legal documents.



## Advance Medical Directives

An advance health care directive must be drawn up before the patient becomes incapacitated.

This document allows the patient to appoint a trusted person to make medical and health decisions when the individual can no longer do so. Sometimes these documents go into effect immediately, while others become active when a specified event occurs.

It is important to choose the administrator carefully and to fully discuss detailed wishes. This legal agent should be someone who knows the patient very well but can remain level-headed and flexible in the face of change and emotional stress. The individual who is asked must first agree to take on the responsibility. He or she may need to make final decisions on minor and major medical issues, including life support. Appointing an alternate is advised in case the chosen person—who has the right to withdraw

from the agreement—is not willing or able to carry out the duties.

Advance health care directives allow patients, while they are still able, to decide upon and express their wishes regarding end-of-life care. Later, they may no longer be capable of communicating these desires. With an advance health care directives, the patient can carefully consider what measures should be taken to prolong life. Often, specifying these actions eases the emotional burden of the loved ones. A living will may contain a “do not resuscitate” order and other treatment limitations that instruct health care personnel not to perform aggressive medical interventions in situations where they might be used. If a physician or facility cannot honor a living will, they must inform the patient or the patient’s representative and assist in transferring the patient to a facility that will honor it.

## Finance-related Documents

In establishing a *durable power of attorney for finances*, the individual authorizes a family member, friend, or professional to act as an agent or proxy on his or her behalf in making financial decisions including banking, investments, tax, and retirement matters. While the individual can direct his or her proxy, it is imperative that this person is carefully chosen, trustworthy, and exercises good judgment, especially as the Alzheimer's patient becomes incapacitated.

If the person with Alzheimer's becomes legally incompetent before a durable power of attorney for finances can be drawn up, or if there is disagreement regarding the proxy, a conservatorship or guardianship may have to be established through the court to handle financial matters. Although it has the advantage of legal supervision, a conservatorship can be expensive and time consuming to establish, requiring an investigation, a hearing, and a judgment about the individual's competency. It is normally easier and quicker to establish a durable power of attorney for finances as soon as possible. A conservator does not make health decisions.

A *will* details how an individual's assets and estate will be divided upon death. Since the person must be of sound mind, a will should ideally be in place before an Alzheimer's diagnosis. A newly diagnosed patient, family member, or professional should ensure that a will has been completed and is up to date. In the absence of a will, each state determines distribution of assets, which typically go to spouses, children, or other family members. Some people choose to establish a *living trust* to distribute assets after death. A living trust is established when the *grantor* (i.e., the person with Alzheimer's) designates someone to serve as the trustee. The trustee manages assets of the trust and ensures proper distribution of them after the grantor's death.

**Usually, the primary caregiver will be a loved one—a spouse, an adult child, or a close companion. Even in the early stages of Alzheimer's, caregiving can be an extremely demanding, 24-hour-a-day task.**



# Caregiving



## For Those Who Live Alone

Some patients continue to live alone in the early stages of Alzheimer's. If so, family members, friends, or neighbors should check on the person daily to see if assistance is needed. Someone close should have an extra set of house keys as well as emergency contact information.

There are a variety of services available for people with Alzheimer's who live by themselves. These may be paid or free and include in-home assistance, housekeeping, meal preparation, and transportation. Family members, friends, neighbors, local religious organizations, and community

volunteer groups can help with other practical matters such as shopping and medical appointments. Physicians, local Agencies on Aging, and organizations listed in the BrightFocus Alzheimer's Disease Resource List can provide information on available services.

At some point, the person with Alzheimer's will be unable to perform daily tasks and require more care and supervision. This will usually be determined by those who are in closest contact, but they may want

to ask others to help discuss plans with the Alzheimer's patient. It is best to carefully consider long-term care options as early as possible, before a serious event forces a less-than-ideal choice. Safety is paramount, and once it is apparent that the person with Alzheimer's is not safe living alone, there should be a transition to a place that offers more assistance. If the person resists a transfer, it may be helpful to create an excuse (e.g., work is being done on the home) or persuade him or her that the situation is temporary (even though it is permanent).



## Staying Active

Keeping active on all levels can be helpful to those with Alzheimer's disease. Although some newly diagnosed patients may want to withdraw from their usual activities out of depression or embarrassment, doing so can actually worsen a person's condition. Even while recognizing their limitations, patients can prolong the quality of life by maintaining a healthy level of stimulation physically, mentally, and socially, and by avoiding stress, which can tax memory and concentration.

Suggestions for beneficial activities include:

- ▲ Interaction with others, including family, friends, children, and pets. Visitors can provide an appreciated human connection.
- ▲ Engaging in creative activities, favorite pastimes, and hobbies; playing games and solving puzzles.
- ▲ Listening to music, which can have a calming effect and trigger vivid memories of the past; singing familiar tunes.
- ▲ Looking at photographs and home videos, which can stimulate the mind, elicit memories, and offer a calming sense of continuity.
- ▲ Performing simple household tasks that do not rely too much on memory, like meal preparation, gardening, or light cleaning.
- ▲ Taking part in activities such as being taken for a drive, going on nature outings or to the zoo, and visiting quiet museums or art galleries. These should be shared with a companion who can ensure safety.
- ▲ Initiating or continuing a light, regular exercise routine.



## Getting involved in a support group.

In support groups, people with Alzheimer's are often better able to come to grips with this disease and the future by expressing their feelings and thoughts to others. For many Alzheimer's patients, support groups help in digesting the news of the diagnosis, overcoming denial, and adjusting to the changes in their lives. Support groups offer practical advice on dealing with memory loss,

social situations, and adjustments in day-to-day living, as well as providing information on community resources. They may offer activities designed to stimulate memory and keep the mind active. These groups can contribute greatly to the quality of life. Consult the BrightFocus Alzheimer's Disease Resource List for ways to find support groups.



## Role of the Caregiver

Usually, the primary caregiver will be a loved one—a spouse, an adult child, or a close companion. Even in the early stages of Alzheimer’s, caregiving can be an extremely demanding, 24-hour-a-day task. Caregivers need to be flexible and understanding in dealing with changes in behavior and personality. They must also be able to communicate with family, friends, and professionals about their loved one’s condition.

Many resources and books offer advice on dealing with those who have Alzheimer’s disease; keep these resources handy. (Many can be found in the BrightFocus Alzheimer’s Disease Resource List). In some communities, caregiver consultation and counseling is available. Although each individual is different, there are many strategies that can be used to make life easier for both the patient and the caregiver.

Recommended strategies include:

- ▲ Speaking clearly and simply while looking the person in the eye; giving easily understood instructions in a normal tone of voice.
- ▲ Compensating for changing capacities and assisting in remembering information. Memory aids such as small books with names, addresses, phone numbers, directions, maps, and ideas can be useful. The patient or caregiver can label items around the house, post reminders for daily tasks, keep calendars with appointments, and label photos with information about those pictured.
- ▲ Maintaining contact with the Alzheimer’s patient’s physician through regular updates on any changes in routine, behavior, or moods. Ongoing or new treatments for Alzheimer’s disease and associated symptoms, as well as therapy for other medical issues should be discussed. The

patient and family may also want to consider participating in clinical trials that test possible new Alzheimer's treatments or investigating Alzheimer's disease-related issues. Information about ongoing trials can be found at [clinicaltrials.gov](http://clinicaltrials.gov), [researchmatch.org](http://researchmatch.org), and other websites in the BrightFocus Alzheimer's Disease Resource List.

- ▲ Establishing routines. The familiar is calming for those with Alzheimer's disease, and they may enjoy simple, repetitive tasks. Choose things they can succeed at to optimize pleasure and minimize frustration.
- ▲ Engaging the person in simple activities that build on current skills, rather than attempting to teach new ones. The patient will likely continue to be interested in and enjoy familiar pastimes. Keep in mind that some times of the day may be better than others

for proposing activities, and the individual should not be forced into doing anything. Mental state can also change from day to day.

- ▲ Using "validation" to enter the person's world. It is very unlikely that the caregiver or anyone else will be able to change the patient's concept of reality. It is much easier to respond positively rather than try to correct misconceptions. Avoid arguing with the person, as it will only frustrate both the patient and the caregiver.
- ▲ Using redirection and distraction if the person wishes to do something that is not possible (e.g., drive a car). Often, presenting an appealing option will succeed.

Avoiding situations and environmental factors like noisy crowds and violent TV programs that may frighten or agitate the patient. Often agitation is a way of communicating stress, and modifying the atmosphere may change the behavior.



## Caregiver Stress

Fulfilling and adapting to the changing needs of the person with Alzheimer's, dealing with unfamiliar behavior and practical matters, and handling the grief of eventual loss takes a physical and emotional toll on caregivers. Those with Alzheimer's and their caregivers should discuss with each other the many aspects of this disease as soon as possible. Early communication can help alleviate the caregivers' guilt and frustration in the future. However, even in the best circumstances, caregivers often become both physically and emotionally exhausted, making them susceptible to illness and depression. To avoid this, caregivers need to focus on their own health and recognize the signs of stress. They may experience denial, depression, irritability, anger, and anxiety, as well as physical warnings such as trouble sleeping, exhaustion, and health problems.

There are many ways to relieve pressure and reduce the stress of caregiving, some of which include: taking time out to relax, engaging in an enjoyable pastime, keeping a list of tasks, writing in a journal, maintaining a sense of humor, eating

right, exercising, and getting proper rest. Caregivers earn the right to give themselves credit for doing the best they can in a very trying situation.

As the disease progresses, the individual with Alzheimer's will become more dependent and less able to participate in many activities. The primary caregiver may become resentful and feel underappreciated and isolated. Any encouragement, emotional support, and social interaction family and friends can provide the caregiver are therefore especially important in helping to avert these negative feelings. The caregiver should be able to turn to receptive family members, friends, or professionals for practical assistance as well. Those close to the caregiver need to provide necessary respite and share in caregiving as much as possible. Out-of-town family members should regularly communicate and offer to help with those responsibilities that can be undertaken from a distance. They can explore and turn to community services. In this way, the caregiver will establish a support network of resources.

## Caregiver Support Groups

Many caregivers can greatly benefit from participation in support groups, some of which meet physically on a regular basis and others that communicate on the Internet. Both offer advice, information, resources, and comfort. Sometimes family members and friends are not as responsive or sympathetic as the

caregiver would like. Those in support groups may have a greater understanding because they are in similar situations. Many become like family or close friends as they discuss common problems, coping strategies, and caring for oneself as well as the Alzheimer's patient. Support groups can be located using the BrightFocus Alzheimer's Disease Resource List.



## Caregiving Options for the Future

There are several caregiving options that may be divided into two categories: short-term care offered in the home or as temporary care outside the home, and long-term care facilities. It is important to plan caregiving early and take into consideration the desires of the person with Alzheimer's, the current and anticipated necessary levels of care, location, and budget constraints. Financial assistance may be available for some short-term care services. However, Medicare does not cover long-term care, so those facilities must be financed through private insurance plans, loans, and personal savings. If these funds are depleted,

Medicaid may be used to pay for continued care. Although the cost will fluctuate depending on real estate market trends, location, and the level of services or amenities, long-term care is expensive. The entire financial situation needs to be carefully evaluated to determine available resources. Organizations listed in the BrightFocus Alzheimer's Disease Resource List offer more information on each type of care, how to assess what type is needed for the individual, and locating and evaluating facilities.

## Short-term and Temporary Care

*Home health agencies* provide support services to the Alzheimer's patient in the home and access to outside care if necessary. Services can include skilled care such as rehabilitation and administering injections, custodial care (cleaning, meal preparation, etc.), companionship, and transportation. Medicare does not cover this type of care. When choosing an agency, check into licensing, staff credentials, and whether the agency provides the needed level of care and is affordable.

*Adult day centers* provide structured programs in which the patient is dropped off in the morning and picked up in the afternoon or evening. Participants can spend the day engaged in supervised activities such as games, craft projects, and light exercise. Some programs also offer meals, transportation, and even professional services such as counseling and physical therapy. Adult day services are often a pleasant prospect for both the patient and

the caregiver, who may use the time to take a break from patient-care responsibility. Costs vary, depending on services. These programs must be paid for privately, but some may be subsidized, as the majority of such organizations are operated on a nonprofit or public basis.





## Long-term Care

*Independent living* or retirement communities are for seniors who are generally healthy and able to care for themselves, so these are not usually a long-term solution for those with Alzheimer's. They offer housing with recreational, educational, and social activities geared specifically to older people. Meals, housekeeping, transportation, and planned activities may also be available. Some communities offer a wide variety of amenities, including golf, tennis, pools, and fitness centers. Costs vary depending on the size of housing, location, services, and amenities. Most communities accept only private methods of payment, but there may be some subsidies for low-income individuals.

*Assisted living facilities* offer private rooms or apartments with in-house care and social activities for older people. In the continuum of care, assisted living bridges the gap between home care and nursing homes. It provides services for those who are not able to live independently

but do not yet require the level of care provided by a nursing home. Many facilities have special sections—called memory care units—for those with Alzheimer's; these are most appropriate for those in the early to middle stages of the disease, who need some regular assistance short of acute medical care. They can offer a home-like setting, 24-hour staff coverage, housekeeping and meal assistance, therapeutic activities, and in-house medical services if needed. Costs for assisted living residences vary greatly, and depend on the size of rooms, amenities, services provided, and location. The residence's management should be able to answer questions concerning base rates, fees for additional services, occupancy levels, staff and their training, ownership, and available assistance programs. Obtaining this information is crucial in choosing the appropriate residence.



*Life care communities or continuing-care retirement communities* offer varying levels of care and typically require a lifetime commitment. They begin as independent living facilities, then offer continued care to residents as they age and their needs change. Residents must be able to live independently at first and may later be transferred from an apartment to an affiliated nursing home for higher levels of care. Some of these communities have special programs for those with Alzheimer's. Normally there is a substantial entrance fee as well as monthly maintenance fees, the costs of which vary greatly depending on the size of the room, amenities, and region of the country.

People with small incomes and savings may investigate naturally occurring retirement communities, which have begun operating in some regions. (Definitions vary somewhat, but a "naturally occurring retirement

community," or *NORC*, is generally area in which fifty percent or so of the residents are 60 or older who have "aged in place," i.e., not moved there specifically for retirement.) For those with resources, full-time live-in care in their own homes may be an option.

Nursing homes or skilled nursing facilities offer long-term, 24-hour care for people with late-stage Alzheimer's. Many facilities have special sections for Alzheimer's patients. They provide rooms, meals, supervised activities, and necessary therapy to residents. Nursing homes must be licensed by the state and certified by Medicare and Medicaid, so they are subject to strict standards, inspections, and evaluations. Medicare does not cover indefinite, long-term care; Medicaid is available for those with low incomes or whose resources are exhausted.

## Hospice Care

*Hospice care* is available in the home or in an assisted living facility for those with terminal illnesses and six months or less to live. In hospice, residents are treated for comfort rather than to cure disease and prolong life. Hospices seek to preserve an individual's dignity and the highest quality of life for as long as possible, while providing

support for family members. Medicare covers the cost of hospice care, and it is available to those with Alzheimer's. However, it is often not used because it is difficult to determine how long the person will live.



## Choosing a Nursing Home

Many caregivers may be unable to care at home for loved ones who are in the final stage of Alzheimer's disease. While the decision to move the person to a nursing home is extremely difficult, it may be the best option. The wisest choices are made when the transition is planned well in advance. Waiting too long could allow a traumatic event to dictate hasty choices and impulsive actions. Family members should consider the needs and wants of the person with Alzheimer's and the caregiver when choosing a facility.

The following may be helpful in deciding on a facility:

- ▲ Gathering information on options soon after diagnosis, so that if the need arises, it will be available.
- ▲ Finding local facilities and setting up appointments to evaluate the accommodations, activities, programs, and services offered; making unannounced visits.
- ▲ Looking closely at staff and their interaction with residents. Finding out if employees are trained to deal specifically with Alzheimer's disease.
- ▲ Observing the demeanor of residents and talking to their family members and visitors.
- ▲ Making sure that the nursing home is clean, well lit, free of unpleasant odors, and has an acceptable noise level.
- ▲ Checking on security if the individual is prone to wandering.
- ▲ Confirming that the nursing home is licensed and certified. Reviewing posted surveys.
- ▲ Carefully reviewing payment options and agreements or contracts.
- ▲ More information on finding and selecting the appropriate nursing home is available on internet sites suggested in the BrightFocus Alzheimer's Disease Resource List.

# Some Final Words

**Many people diagnosed with Alzheimer's report that the more they know and talk about the disease, the better they feel.**

They want to understand what to expect and to share their concerns with loved ones, others who have the disease, professionals, and members of support groups. These interactions can help people feel more in control, less anxious, and better able to take advantage of the current treatments and available sources of assistance. The organizations and publications listed in the BrightFocus Alzheimer's Disease Resource List are valuable resources.

After those with Alzheimer's have adjusted to the new diagnosis and prepared for the future, the emphasis should be on living and coping with the disease. There is still time to enjoy life, even if it's in a different way, and their loved ones can find comfort and support in an ever-growing network of information, new treatments, lifestyle recommendations, and resources.

There is not yet a cure for Alzheimer's disease, but a tremendous amount of research is being carried out by dedicated scientists around the world. In recent years, real progress has been made. Our understanding of this complicated disease has increased enormously, and as the pieces of the puzzle begin to come together, we move closer to solving the mystery and finding ways to treat, cure, and prevent Alzheimer's.

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There is still time to enjoy life, even if it's in a different way.

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*Living with Alzheimer's Disease* is produced by BrightFocus Alzheimer's Disease Research.

The following publications are available from BrightFocus in English and Spanish:

- ▲ Care for the Caregiver: Managing Stress
- ▲ Safety and the Older Driver
- ▲ Staying Safe: Wandering & the Alzheimer's Patient
- ▲ Understanding Alzheimer's Disease: It's Not Just Forgetfulness

Available in English only:

- ▲ Through Tara's Eyes: Helping Children Cope with Alzheimer's Disease

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Alzheimer's Disease Research  
22512 Gateway Center Drive  
Clarksburg, MD 20871

(301) 948-3244  
1-855-345-6237  
fax (301) 258-9454

info@brightfocus.org  
[www.brightfocus.org/Alzheimers](http://www.brightfocus.org/Alzheimers)  
[www.brightfocus.org/PubsEspanol](http://www.brightfocus.org/PubsEspanol)

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